

## General

### Title

Epilepsy: percentage of patients with a diagnosis of epilepsy with seizure frequency greater than 0 for whom an intervention to reduce seizure frequency was offered or discussed with the patient or caregiver.

### Source(s)

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

## Measure Domain

### Primary Measure Domain

Clinical Quality Measures: Process

### Secondary Measure Domain

Does not apply to this measure

## Brief Abstract

### Description

This measure is used to assess the percentage of patients with a diagnosis of epilepsy with seizure frequency greater than 0 for whom an intervention to reduce seizure frequency was offered or discussed with the patient or caregiver.

### Rationale

The main objective in treating epilepsy is to reduce the frequency of seizures and achieve seizure freedom without side effects. An intervention should be considered when patients are not seizure-free, because if intervention is provided seizure freedom may be achieved (Fisher & Handforth, 1999; French et al., "Treatment of new onset epilepsy," 2004; French et al., "Treatment of refractory epilepsy," 2004; Wiebe et al., 2001; Engel et al., 2003; Morris et al., 2013).

The following clinical recommendation statements are quoted verbatim from the referenced clinical guidelines and represent the evidence base for the measure:

"All of the new antiepileptic drugs (AEDs) were found to be appropriate for adjunctive treatment of refractory partial seizures in adults." "The choice of AED depends upon seizure and/or syndrome type, patient age, concomitant medications, AED tolerability, safety, and efficacy" (Fisher & Handforth, 1999).

The decision to initiate AED therapy should be taken between the child, young person or adult, their family and/or carers (as appropriate) and the specialist after a full discussion of the risks and benefits of treatment. This discussion should take into account details of the person's epilepsy syndrome, prognosis and lifestyle (National Institute for Health and Clinical Excellence [NICE], 2012).

It is recommended that combination therapy (adjunctive or 'add-on' therapy) should only be considered when attempts at monotherapy with AEDs have not resulted in seizure freedom. If trials of combination therapy do not bring about worthwhile benefits, treatment should revert to the regimen (monotherapy or combination therapy) that has proved most acceptable to the child, young person or adult, in terms of providing the best balance between effectiveness in reducing seizure frequency and tolerability of side effects (NICE, 2012).

If the patient continues to have seizures after initiating treatment then interventions should be performed (Pugh et al., 2007).

Vagus nerve stimulation (VNS) is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults who are refractory to antiepileptic medication but who are not suitable for resective surgery. This includes adults whose epileptic disorder is dominated by focal seizures (with or without secondary generalization) or generalised seizures (NICE, 2012).

Evidence exists to rank VNS for epilepsy as effective and safe, based on a preponderance of Class I evidence (Fisher & Handforth, 1999).

## Opportunity for Improvement

Evidence indicates treatment interventions that may result in seizure freedom are not offered in a timely manner. There is likely a group of patients who have treatment resistant (intractable) epilepsy by definition (Kwan et al., 2010) but are not considered by their medical care provider to be treatment resistant because the seizures are considered mild or "infrequent." This measure will assess the degree to which all patients with epilepsy receive timely intervention. The opportunity for improvement is evident in many studies demonstrating that patients are not being offered efficacious interventions. For example, the duration of epilepsy before surgery is offered remains almost 20 years despite strong evidence of efficacy of epilepsy surgery and after the release of a guideline recommending referral (Haneef et al., 2010).

## Evidence for Rationale

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

Engel J Jr, Wiebe S, French J, Sperling M, Williamson P, Spencer D, Gumnit R, Zahn C, Westbrook E, Enos B. Practice parameter: temporal lobe and localized neocortical resections for epilepsy: report of the Quality Standards Subcommittee of the American Academy of Neurology, in association with the American Epilepsy Society and the AANS [trunc]. *Neurology*. 2003 Feb 25;60(4):538-47. [69 references] [PubMed](#)

Fisher RS, Handforth A. Reassessment: vagus nerve stimulation for epilepsy: a report of the Therapeutics and Technology Assessment Subcommittee of the American Academy of Neurology. *Neurology*. 1999 Sep 11;53(4):666-9. [PubMed](#)

French JA, Kanner AM, Bautista J, Abou-Khalil B, Browne T, Harden CL, Theodore WH, Bazil C, Stern J, Schachter SC, Bergen D, Hirtz D, Montouris GD, Nespeca M, Gidal B, Marks WJ Jr, Turk WR, Fischer JH, Bourgeois B, et al. Efficacy and tolerability of the new antiepileptic drugs I: treatment of new onset epilepsy: report of the Therapeutics and Technology Assessment Subcommittee and Quality Standards

Subcommittee of the American Academy of Neurology and the AES. Neurology. 2004 Apr 27;62(8):1252-60. [21 references] [PubMed](#)

French JA, Kanner AM, Bautista J, Abou-Khalil B, Browne T, Harden CL, Theodore WH, Bazil C, Stern J, Schachter SC, Bergen D, Hirtz D, Montouris GD, Nespeca M, Gidal B, Marks WJ Jr, Turk WR, Fischer JH, Bourgeois B, et al. Efficacy and tolerability of the new antiepileptic drugs II: treatment of refractory epilepsy: report of the Therapeutics and Technology Assessment Subcommittee and Quality Standards Subcommittee of the American Academy of Neurology and the AES. Neurology. 2004 Apr 27;62(8):1261-73. [83 references] [PubMed](#)

Haneef Z, Stern J, Dewar S, Engel J. Referral pattern for epilepsy surgery after evidence-based recommendations: a retrospective study. Neurology. 2010 Aug 24;75(8):699-704. [PubMed](#)

Kwan P, Arzimanoglou A, Berg AT, Brodie MJ, Allen Hauser W, Mathern G, Moshé SL, Perucca E, Wiebe S, French J. Definition of drug resistant epilepsy: consensus proposal by the ad hoc Task Force of the ILAE Commission on Therapeutic Strategies. Epilepsia. 2010 Jun;51(6):1069-77. [PubMed](#)

Morris GL 3rd, Gloss D, Buchhalter J, Mack KJ, Nickels K, Harden C. Evidence-based guideline update: vagus nerve stimulation for the treatment of epilepsy. Report of the Guideline Development Subcommittee of the American Academy of Neurology. Neurology. 2013 Oct 15;81(16):1453-9. [40 references] [PubMed](#)

National Institute for Health and Clinical Excellence (NICE). The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. London (UK): National Institute for Health and Clinical Excellence (NICE); 2012 Jan. 117 p. (Clinical guideline; no. 137).

Pugh MJ, Berlowitz DR, Montouris G, Bokhour B, Cramer JA, Bohm V, Bollinger M, Helmers S, Ettinger A, Meador KJ, Fountain N, Boggs J, Tatum WO 4th, Knoefel J, Harden C, Mattson RH, Kazis L. What constitutes high quality of care for adults with epilepsy. Neurology. 2007 Nov 20;69(21):2020-7. [40 references] [PubMed](#)

Wiebe S, Blume WT, Girvin JP, Eliasziw M, Effectiveness and Efficiency of Surgery for Temporal Lobe Epilepsy Study Group. A randomized, controlled trial of surgery for temporal-lobe epilepsy. N Engl J Med. 2001 Aug 2;345(5):311-8. [PubMed](#)

## Primary Health Components

Epilepsy; seizure frequency; intervention

## Denominator Description

All visits for patients with a diagnosis of epilepsy with a seizure frequency greater than 0 (see the related "Denominator Inclusions/Exclusions" field)

## Numerator Description

Patient visits where an intervention to reduce seizure frequency was offered/discussed with patient or caregiver (see the related "Numerator Inclusions/Exclusions" field)

## Evidence Supporting the Measure

# Type of Evidence Supporting the Criterion of Quality for the Measure

A clinical practice guideline or other peer-reviewed synthesis of the clinical research evidence

A formal consensus procedure, involving experts in relevant clinical, methodological, public health and organizational sciences

One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

## Additional Information Supporting Need for the Measure

### Importance of Topic

Epilepsy data is lacking. In 2012, the Institute of Medicine released *Epilepsy across the Spectrum: Promoting Health and Understanding*, detailing epilepsy research disparities and highlighting specific areas where further research is needed, including the extent of epilepsy, consequences, comorbid conditions and outcomes of epilepsy (England et al., 2012). The following statistics only touch on the magnitude of epilepsy given lack of research and stigma:

It is estimated 2.2 million people in the United States are diagnosed with epilepsy, and 150,000 new cases of epilepsy are diagnosed in the United States annually (England et al., 2012).

Epilepsy prevalence might be underestimated because of underreporting associated with repercussions and stigma in disclosing epilepsy (Kobau et al., 2012).

Common comorbidities among people with epilepsy include somatic (i.e., fractures, asthma, diabetes, and heart disease), neurological (i.e., stroke, Alzheimer's disease, autism spectrum disorders, chronic pain), and mental health conditions (i.e., mood disorders, attention deficit hyperactivity disorders, anxiety disorders, suicidality) (England et al., 2012; Kobau et al., 2008).

It is estimated the number of people with epilepsy who die of sudden unexpected death in epilepsy (SUDEP) range from 1 of every 10,000 who are newly diagnosed to 9 of every 1,000 candidates for epilepsy surgery (England et al., 2012).

People with epilepsy are more likely to be unemployed or unable to work, have low annual household incomes, be obese and physically inactive, and to smoke (England et al., 2012; Kobau et al., 2008).

People with epilepsy have poorer overall health status, impaired intellectual and physical functioning, a greater risk for accidents and injuries, and negative side effects from seizure medications (Fountain et al., 2011; England et al., 2012; Kobau et al., 2008).

It is estimated the annual direct medical cost of epilepsy in the United States is \$9.6 billion. This estimate does not include community service costs or indirect costs from losses in quality of life and productivity (England et al., 2012).

### Opportunities for Improvement

Additional data on opportunities for improvement and gaps in care specific to the epilepsy measures can be located in the updated epilepsy measures.

A review of 261 patient responses using the PatientsLikeMe survey system indicated a gap remains between recommended care detailed in the 2009 epilepsy measurement set and the care delivered to patients with epilepsy (Wicks & Fountain, 2012).

The Institute of Medicine noted several gaps in care and opportunities for improvement, including 1) timely referrals and access to treatments, 2) epilepsy care and prevention, 3) education of persons with epilepsy and their families, and 4) the stigma of epilepsy (England et al., 2012).

Surgery continues to be heavily underutilized as a treatment for epilepsy, with significant disparities by race and insurance coverage (Englot et al., 2012).

## Evidence for Additional Information Supporting Need for the Measure

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

England MJ, Liverman CT, Schultz AM, Strawbridge LM. Epilepsy across the spectrum: promoting health and understanding. 1st ed. Washington (DC): The National Academies Press; 2012.

Englot DJ, Ouyang D, Garcia PA, Barbaro NM, Chang EF. Epilepsy surgery trends in the United States, 1990-2008. *Neurology*. 2012 Apr 17;78(16):1200-6. [PubMed](#)

Fountain NB, Van Ness PC, Swain-Eng R, Tonn S, Bever CT Jr, American Academy of Neurology Epilepsy Measure Development Panel and the American. Quality improvement in neurology: AAN epilepsy quality measures: Report of the Quality Measurement and Reporting Subcommittee of the American Academy of Neurology. *Neurology*. 2011 Jan 4;76(1):94-9. [PubMed](#)

Kobau R, Luo YH, Zack MM, et al. Epilepsy in adults and access to care--United States, 2010. *MMWR Morb Mortal Wkly Rep*. 2012 Nov 16;61(45):909-13. [PubMed](#)

Kobau R, Zahran H, Thurman DJ, Zack MM, Henry TR, Schachter SC, Price PH, Centers for Disease Control and Prevention (CDC). Epilepsy surveillance among adults--19 States, Behavioral Risk Factor Surveillance System, 2005. *Morb Mortal Wkly Rep Surveill Summ*. 2008 Aug 8;57(6):1-20. [PubMed](#)

Wicks P, Fountain NB. Patient assessment of physician performance of epilepsy quality-of-care measures. *Neurol Clin Pract*. 2012 Dec;2(4):335-42. [PubMed](#)

## Extent of Measure Testing

The new epilepsy measures are being made available without any prior testing. The American Academy of Neurology encourages testing of this measurement set for feasibility and reliability by organizations or individuals positioned to do so.

## Evidence for Extent of Measure Testing

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

## State of Use of the Measure

### State of Use

Current routine use

### Current Use

not defined yet

## Application of the Measure in its Current Use

### Measurement Setting

## Measurement Setting

Ambulatory/Office-based Care

Hospital Outpatient

## Professionals Involved in Delivery of Health Services

not defined yet

## Least Aggregated Level of Services Delivery Addressed

Individual Clinicians or Public Health Professionals

## Statement of Acceptable Minimum Sample Size

Does not apply to this measure

## Target Population Age

Unspecified

## Target Population Gender

Either male or female

## National Strategy for Quality Improvement in Health Care

### National Quality Strategy Aim

Better Care

### National Quality Strategy Priority

Prevention and Treatment of Leading Causes of Mortality

## Institute of Medicine (IOM) National Health Care Quality Report Categories

### IOM Care Need

Living with Illness

### IOM Domain

Effectiveness

# Data Collection for the Measure

## Case Finding Period

Unspecified

## Denominator Sampling Frame

Patients associated with provider

## Denominator (Index) Event or Characteristic

Clinical Condition

Encounter

## Denominator Time Window

not defined yet

## Denominator Inclusions/Exclusions

### Inclusions

All visits for patients with diagnosis of epilepsy with a seizure frequency greater than 0

Note: Refer to the original measure documentation for International Classification of Diseases, Ninth Revision (ICD-9), International Classification of Diseases, Tenth Revision (ICD-10), and Current Procedural Terminology (CPT) Evaluation and Management (E/M) service codes.

### Exclusions

Unspecified

### Exceptions

Caregiver is unavailable for a patient who is non-communicative or has an intellectual disability.  
No appropriate intervention available for the patient.

## Exclusions/Exceptions

not defined yet

## Numerator Inclusions/Exclusions

### Inclusions

Patient visits where an intervention to reduce seizure frequency\* was offered/discussed with patient or caregiver

\**Intervention to Reduce Seizure Frequency*: Change in anti-seizure medication or dose modification, medication adherence counseling, referral for surgery, or discussion about change in therapy.

### Exclusions

Unspecified

## Numerator Search Strategy

Fixed time period or point in time

## Data Source

Administrative clinical data

Electronic health/medical record

## Type of Health State

Does not apply to this measure

## Instruments Used and/or Associated with the Measure

Unspecified

## Computation of the Measure

### Measure Specifies Disaggregation

Does not apply to this measure

## Scoring

Rate/Proportion

## Interpretation of Score

Desired value is a higher score

## Allowance for Patient or Population Factors

not defined yet

## Standard of Comparison

not defined yet

## Identifying Information

### Original Title

Measure #1B: seizure intervention (paired measure).

# Measure Collection Name

Epilepsy Quality Measurement Set

## Submitter

American Academy of Neurology - Medical Specialty Society

## Developer

American Academy of Neurology - Medical Specialty Society

## Funding Source(s)

American Academy of Neurology

## Composition of the Group that Developed the Measure

Epilepsy 2014 Update Work Group Members

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*American Clinical Neurophysiology Society:* Susan T. Herman, MD

*American College of Emergency Physicians:* J. Stephen Huff, MD

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*American Society of Neuroradiology/American College of Radiology:* Marvin Nelson, MD

*Child Neurology Society:* Inna Hughes, MD, PhD

*Citizens United for Research in Epilepsy:* Tracy Dixon-Salazar, PhD

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## Financial Disclosures/Other Potential Conflicts of Interest

Unspecified

## Endorser

American Epilepsy Society - Medical Specialty Society

Child Neurology Society - Medical Specialty Society

Epilepsy Foundation - Medical Specialty Society

## Date of Endorsement

American Epilepsy Society: 2013 Jul 29

Child Neurology Society: 2014 Jul 29

Epilepsy Foundation: 2014 Aug 7

## Adaptation

This measure was not adapted from another source

## Date of Most Current Version in NQMC

2014 Jan

## Measure Maintenance

Unspecified

## Date of Next Anticipated Revision

Unspecified

## Measure Status

This is the current release of the measure.

## Measure Availability

Source available from the [American Academy of Neurology \(AAN\) Web site](#) .

For more information, contact AAN at 201 Chicago Avenue, Minneapolis, MN 55415; Phone: 800-879-1960; Fax: 612-454-2746; Web site: [www.aan.com](#) .

## NQMC Status

This NQMC summary was completed by ECRI Institute on January 6, 2016. The information was not verified by the measure developer.

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## Production

## Source(s)

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